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ABSTRACT

The effectiveness of independent living programs for developmentally disabled persons in Los Angeles County was examined using a sample of 33 clients (ages 18-50) who exited such programs between June 1984 and June 1986. All but one were mentally retarded; seven also had either cerebral palsy or epilepsy. Survey forms for each client were completed through reviews of case records and interviews with administrators at the three participating training program offices. The characteristics of the 22 clients who successfully maintained independent living were compared with those who did not achieve and/or maintain it. Tables present data and cross tabulations on age at entry to program, type of disability, presence of dual diagnosis, ethnicity, length of attendance, status at termination, and living situation before, during, and after participation. The programs were found to be reasonably effective in training individuals with developmental disabilities to live independently, but the small sample size diminished the ability to draw conclusions about the correlation of specific characteristics with success or failure. Appendices include copies of survey instruments and overall tallies of the data. (VW)

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THE EFFECTIVENESS OF INDEPENDENT LIVING TRAINING PROGRAMS IN LOS ANGELES COUNTY FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

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A THESIS

Presented to the Department of Social Work

California State University, Long Beach

In Partial Fulfillment

of the Requirements for the Degree

Master of Social Work

By Nancy E. White

MS, 1982, California State University, Long Beach

May 1987

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THE EFFECTIVENESS OF INDEPENDENT LIVING TRAINING PROGRAMS IN LOS ANGELES COUNTY FOR INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES

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Chapter 1

Introduction

Within the past 25 years, individuals with developmental disabilities have been provided with an increasing number of options for residential care. Large segregated institutions were the only choice several decades ago. However, the philosophies of deinstitutionalization and normalization have supported the provision of various types of community-based residential settings. Independent living training programs are the most recently developed alternatives to institutional care. They also represent the least restrictive, or most normalized, settings.

Purpose of the Project

The purpose of this project was to examine the effectiveness of independent living training programs in Los Angeles County. More specifically, the researcher attempted to determine the percentage of developmentally disabled clients who achieved and maintained an independent living status after exiting an independent living training program in Los Angeles County between June, 1984 and June, 1986. A second purpose was to compare the characteristics of those clients who successfully maintained independent living with those clients who did not achieve and/or maintain independent living.

Statement of the Problem

Are independent living training programs in Los Angeles County effectively training individuals with developmental disabilities to live independently?

Which client characteristics are associated with successful independent living?

Significance of the Project

Although the success of the deinstitutionalization movement has been documented, most studies have addressed community placements which provide 24 hour per day supervision. Few studies have evaluated the effectiveness of independent living training programs. New programs of this nature are being designed and implemented, yet researchers and practitioners have no conclusive evidence of their success. One significance of this project, then, is to provide new data regarding the characteristics and outcomes of developmentally disabled persons who received independent living training. The results will potentially benefit funding agencies and service providers. In addition, the project may benefit developmentally disabled persons who are current or future candidates for independent living training programs.

The project is of value to the social work profession as social workers are employed in a variety of roles with independent living training programs. For example, social workers may be responsible for the planning and

implementation of such programs. Direct service to the clients and their families is often provided by social workers; and, perhaps even more commonly, social workers serve as administrators, consultants, and monitors of independent living training programs. The project will, then, add to the basic core of social work knowledge.

Definition of Terms

The following terms are defined in order to clarify their meaning within the context of the study.

Developmental Disability

Developmental disability refers to a disability that becomes evident in childhood, is expected to continue indefinitely, constitutes a substantial handicap to the affected individual, and is attributable to mental retardation, cerebral palsy, epilepsy, autism, or other neurological conditions requiring similar treatment (Deering's 1978; Gunn 1975).

Independent Living Training Program

An independent living training program is a program which provides comprehensive training directed toward assisting developmentally disabled individuals to move into self-sustaining independent living situations in the community (Californians 1986). For the purpose of the present study, this term refers to residential apartment

training programs in which clients receive intensive skills training. The term does not refer to those programs/services which provide limited training to help clients maintain an independent living status.

Successful Independent Living

For the purposes of the present study, successful independent living refers to living in the community alone or with a roommate for a minimum of six months. If the housing is shared, it is assumed that the roommate does not provide any care or training to the client. Examples of housing considered to accommodate individuals successfully living independently are apartments, houses, and mobile homes. Supervised residential settings, hotels, shelters, or living on the streets are not considered successful independent living arrangements.

Chapter 2

Review of Related Literature

The literature reviewed for this project was found in books, periodicals, and unpublished sources written between the years 1971 and 1986. The literature presented herein represented an attempt to provide an accurate definition of developmental disabilities; an overview of current policies, programs, and services for developmentally disabled; a description of the impetus for the development of independent living training programs; and an examination of the effectiveness of independent living training programs.

Definition of Developmental Disabilities

The term developmental disability is the most recent version of a concept that originated in the late 1960s when the term "mental retardation" was thought to be too restrictive. In 1970, PL 91-517 coined and defined developmental disability as:

> . . . a disability attributable to mental retardation, cerebral palsy, epilepsy, or other neurological handicapping conditions of an individual found to be closely related to mental retardation or to require treatment similar to that required by mentally retarded individuals, and the disability originates before such an individual attains age 18 and has continued, or is expected to continue indefinitely and constitutes a substantial handicap of such individuals. (Summers 1981, p. 259)

Because many states, when interpreting the Federal legislation, tended to concentrate solely on the first

three conditions and ignore the more broad fourth category, "other neurological handicapping conditions," Congress sought to amend PL 91-517. In 1975, PL 94-103 attempted to broaden the earlier definition by adding autism and some forms of dyslexia to the list of previously stated conditions. However, some Congressional members felt that PL 94-103 was unnecessary in that disability categories should not need to be continually added to the original definition, if that definition is interpreted correctly by the states. Therefore, a task force was given the responsibility of studying the definition. As a result, the Developmental Disabilities Act was further amended in 1978 by the passing of PL 95-602 which defines the term as:

> A developmental disability is a severe, chronic disability of a person which (A) is attributable to a mental or physical impairment, or combination of mental and physical impairments; (B) is manifested before the person attains age 22; (C) is likely to continue indefinitely; (D) results in substantial functional limitations in three or more of the following areas of major life activity: (i) self-care, (ii) receptive and expressive language, (iii) learning, (iv) mobility, (v) self-direction, (vi) capacity for independent living, and (vii) economic self-sufficiency; and (E) reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which are individually planned and coordinated. (Summers 1981, p. 259)

Federal legislation currently maintains the above definition. There are varying legal definitions according to state codes. In California, the Lanterman Developmental Disabilities Act of 1978, Section 4512 of the Welfare and Institutions Code, defines developmental disability as:

> . . . a disability which originates before an individual attains age 18, continues, or can be expected to continue, indefinitely, and constitutes a substantial handicap for such individual. As defined by the Director of Developmental Services, in consultation with the Superintendent of Public Instruction, this term shall include mental retardation, cerebral palsy, epilepsy, and autism. This term shall also include handicapping conditions found to be closely related to mental retardation or to require treatment similar to that required for mentally retarded individuals, but shall not include other handicapping conditions that are solely physical in nature. (Deering's 1978, p. 55)

In conclusion, there is an infinite number of possible definitions of developmental disability, including many variations of the subcategories of mental retardation, cerebral palsy, epilepsy, and autism. There are many ranges of intellectual functioning and adaptive behaviors within the scope of mental retardation. There are basically four divisions of retardation: mild, moderate, severe, and profound. Even within the same range of severity, no two persons are alike, just as is true with non-disabled people. And, as with mental retardation, there are different ranges of functioning associated with cerebral palsy, epilepsy, and autism. Many people with these disabilities are not mentally retarded, either in intellectual abilities or adaptive behaviors (Payne and Patton 1981).

Current Policies, Programs, and Services

The current policies affecting the provision of services to developmentally disabled persons are based on

four main philosophical trends: the human rights movement, deinstitutionalization, normalization, and the concept of least restrictive environment. These issues will be discussed at length in this literature review under the heading, "Impetus for Development of Independent Living Training Programs."

Each state in the United States is federally mandated to develop a statewide plan for the provision of services to developmentally disabled persons. Regional coordinating agencies have been formulated in many states to provide a continuum of care for each developmentally disabled person in its catchment area. For example, in California, the Department of Developmental Services (DDS) administers the developmental disabilities service system. DDS directly operates eight developmental centers (previously known as state hospitals) and contracts with 21 private, nonprofit community organizations known as "regional centers." The regional centers are responsible for intake and diagnostic services for potential clients; individual program planning for clients; and coordination of delivery of services to clients in each catchment area. The regional centers provide direct funding of many programs and services. These include day programs, medical services, recreational programs, respite services, and a variety of specialized residential settings (Californians 1986; Ingalls 1978).

There are many generic agencies and individuals which provide services to the developmentally disabled population. For example, many physicians, dentists, and other specialists provide quality care to persons with developmental disabilities. State, county, and local governmental agencies often have programs designed to meet the needs of special populations. These include recreation, legal, homemaking, and rehabilitative programs. Two major agencies which provide federally mandated services for disabled persons are the Department of Education and the Department of Rehabilitation (Californians 1986). Programs under these auspices will be described in another section of this chapter.

The major income maintenance program which assists developmentally disabled is Supplemental Security Income (SSI). SSI is a federal program which provides monthly payments to aged, blind, and disabled people who have limited income and resources. Many states supplement the basic rate mandated by the federal government. SSI is designed to meet a person's basic living expenses while he/she is living with family, friends, independently, or in a board and care home. In many states, recipients of SSI automatically qualify for Medicaid (known as MediCal in California). Medicaid is a medical assistance program which pays for the medical care of low income persons (US 1985a).

Some persons with developmental disabilities are also eligible for Social Security benefits. Social Security is funded through taxes paid by workers, employers, and self-employed people. Developmentally disabled persons who worked and contributed to the Social Security system may draw their own benefits when they retire or are determined disabled (unemployable). In other cases, unmarried, severely disabled persons can receive benefits from a parent who retired, became disabled, or died. Disabled persons can receive Medicare after two years of being eligible for Social Security. Medicare is a federally funded hospital and medical insurance plan which covers some, but not all, medical expenses (US 1985b).

Services and programs available for individuals with developmental disabilities in the United States will now be described according to age groups.

Infants and Preschoolers

Programs for infants and preschool-aged children with developmental disabilities are proliferating. Recent research has indicated the importance of a child's early years in determining his/her overall course of development (Ingalls 1978). Children with more severe handicaps are likely to be identified earlier. Therefore, most programs for infants and preschoolers are designed for moderately to profoundly handicapped, multihandicapped, or children

identified as high risk for being developmentally disabled (Payne and Patton 1981).

According to Payne and Patton (1981), there are three major models of providing services to delayed infants and preschoolers. First, in the home-based model, a teacher instructs the child and parent(s) in their home. The teacher's main purpose is to identify needs of the child, design a program to meet those needs, instruct the parent in implementing the program, and monitor its success. The program is well suited for families who live in sparsely populated areas or for those families who prefer to instruct their child at home due to medical, emotional, or cultural reasons. Another advantage is that the home-based program allows for teaching in "natural settings" (i.e., where a person actually spends time). However, this model has the disadvantage of isolation--both child and parent(s) do not have the opportunity to interact with other children and parents.

The second model, center-based programs, offer instruction at a centralized location. Usually, teachers and parents work together to provide a combination of individual, small-group, and large-group instruction. This model allows children to interact with other children and adults in preparation for school. Many such programs can provide specialized training by consultation with other

professionals, including physical, language, and occupational therapists and medical personnel.

A combination of the home and center-based programs constitute the third model of providing services to delayed infants and preschoolers. In this model, children and parents participate in programming both at a centralized location and in their home. The amount of time spent in each setting can vary depending on the child's age. For example, some programs will serve those children under three years old within the home, and then begin to transition them into the school setting (Payne and Patton 1981).

Children and Youth

Today, the core of programs for developmentally disabled children and youth are provided by the public education system. A landmark piece of legislation, the 1975 Education for All Handicapped Children Act (PL 94-142), assures the availability of a free, public education in the least restrictive environment for all handicapped persons, ages 3 through 21 years (Payne and Patton 1981). Hohenshill and Humes (1979) summarize the implications of this law as follows:

> PL 94-142 assures that all handicapped children aged 3-21, have a free and appropriate public education in the least restrictive environment possible. The cornerstone of this legislation is the fact that a written Individual Education Program (IEP) must be developed for each handicapped child and be reviewed annually. Another major ingredient of this law

> guarantees various due process procedures for students and their parents. These due process procedures cover the procedural safeguards that govern both evaluation and programming. In terms of educational and psychological evaluations, the parents must be fully informed in their native language and must understand that the granting of consent is voluntary. Further, the parents of a handicapped child are afforded the opportunity to examine all educational records with regard to evaluation and programming. In addition, they have the right to obtain an independent educational evaluation by a qualified outside examiner at public expense, if it can be demonstrated that the public agency (school) evaluation was inappropriate. In essence, PL 94-142 tries to provide handicapped persons with the special additional services that will make them as educationally competitive with non-handicapped students as possible. (p. 222)

Specific alternatives available for school placement of developmentally disabled students can be divided into four major categories: programs based in regular classrooms, in special classrooms, in special schools, and in other settings. Regular class programs most closely approximate the ultimate goal of providing services to developmentally disabled children with minimal segregation from their non-disabled peers. Special materials and equipment can be utilized by regular education teachers to meet the needs of their disabled students. The teachers sometimes receive consultation from special education teachers. Other times, students are placed in regular classrooms but spend part of each day in a resource room. Generally, those students who participate in regular class programs are either learning disabled or mildly mentally retarded (Payne and Patton 1981).

Special classrooms provide a self-contained instructional environment on a regular school campus. They are designed for those students who cannot keep up with the schoolwork presented in a regular classroom. However, students in the special classes often have opportunities for interaction with non-disabled peers during recess, lunch, physical education, art, and music. The self-contained classes are usually restricted to 10-15 students and are taught by a special education teacher and aide (Payne and Patton 1981).

Special schools designed to meet the needs of severely handicapped children provide structured learning environments without the opportunity for integration with non-disabled peers. Although this model allows for manipulation of all variables within the learning environment, students do not have the benefits of modeling and socializing with other children. In severe situations, when a child's disability warrants round-the-clock attention, he/she might attend a residential special school. This option must be considered only when the child cannot effectively function in a less restrictive environment (Payne and Patton 1981).

Other settings which serve developmentally disabled students under special circumstances are hospitals and students' homes. Hospital instruction is usually provided on a temporary basis to children recovering from an illness

or injury. However, it can be a continuous process for those children confined to a hospital for serious, chronic illnesses. Homebound instruction is provided by visiting or regular teachers to those students confined to their home because of illness or injury (Payne and Patton 1981).

Although school programs are designed to meet the primary needs of developmentally disabled children and youth, other programs can supplement the school setting. Such supplemental services can benefit not only the child but also his/her family. Examples of such services include: day care; medical services; psychiatric, psychological, and social work services; recreation programs; behavior modification; respite care; and out-of-home placement (Californians 1986).

Adults

There are a wide variety of programs available to adults with developmental disabilities. Choice of the most appropriate, effective program must be based on consideration of the needs of the individual, the family, and the available community resources. Day programs available to non-institutionalized adults include activity centers, sheltered workshops, community-based training, and competitive employment. Activity centers provide a range of services to moderately or severely retarded adults who are unable to engage in competitive or even sheltered work.

Instruction is provided in the areas of grooming and hygiene, domestic skills, communication, academics, and leisure. Some centers also provide prevocational training with instruction in simple assembly tasks (Ingalls 1978).

The National Association of Sheltered Workshops and Homebound Programs defines a sheltered workshop as follows:

> . . . a nonprofit organization or institution conducted for the purpose of carrying out a recognized program of rehabilitation for physically, mentally, and socially handicapped individuals by providing such individuals with renumerative employment and one or more other rehabilitating activities of an educational, psycho-social, therapeutic, vocational, or spiritual nature. (Payne 1974, p. 249)

Services generally include screening, work evaluation, work adjustment, vocational guidance and counseling, vocational training, placement, and follow-up. Funding for these services is often provided by public agencies, such as the Department of Rehabilitation. Individual competency in a variety of tasks is the primary program focus. The development of work related behaviors is also stressed. These include consistent attendance, promptness, task attention, social skills, grooming, and safety. The various services are typically offered in one large facility. An assortment of job experiences is provided through industrial subcontract work with skills ranging from unskilled assembly line tasks to highly complex assignments (Brolin 1976; Payne and Patton 1981).

Community-based training refers to the instruction of developmentally disabled persons in their "natural"

environments. This means that the traditional settings of classroom and workshop are no longer used exclusively. Instead, instruction is provided in the individual's own community. Banks, restaurants, job sites, recreation centers, and shopping centers are typical sites for instruction and training. Vocational training is only one element of a comprehensive community-based program (Ryan 1985).

Competitive employment refers to work in a non-segregated environment, a "regular job" in the public or private sector. Most developmentally disabled adults who are competitively employed function in the range of mild mental retardation, but some more severely handicapped individuals have been able to maintain employment. Typically, developmentally disabled adults are employed in unskilled or semi-skilled labor, such as janitorial, food service, or factory work. others are self-employed in gardening or domestic trades. With increased opportunities, training, and support, developmentally disabled adults can assume a wider range of competitive jobs (Payne and Patton 1981; Wehman 1981).

Housing for developmentally disabled adults ranges from large institutions to independent living. Community placements can be divided into five main categories: with own families, foster homes, group homes, extended health care facilities, and independent living. Today, most

developmentally disabled adults live with their own families. The majority of families are able and willing to provide quality care and support to the disabled person. However, when the care becomes a burden to parents, siblings, or other relatives, alternate living arrangements are sought (Ingalls 1978).

Foster homes are often considered the most preferable alternative to living with one's own family. Typically, the state pays the foster family for providing care to one or more developmentally disabled persons. This arrangement offers the most "normal" environment and can allow the disabled person to benefit from individual attention. However, some foster families are primarily interested in the financial incentives, and consequently provide inadequate care and support (Ingalls 1978).

Group homes are the most common community living arrangement established by social service agencies for developmentally disabled persons. They can be categorized by size and population. They typically serve a specific age group; children and adults rarely live in the same home. Some homes are exclusively male or female but an increasing number are for both sexes. Group homes generally serve between 5 and 20 persons, although large group homes can accommodate up to 40 persons. The homes are usually located in a residential neighborhood and cannot be physically distinguished from other homes in the

community. Most residents attend school or adult day programs. During the evenings and weekends, training is provided in self-help skills, household management, basic academics, socialization, leisure activities, safety, and mobility (Ingalls 1978; Payne and Patton 1981).

Extended health care facilities provide long-term residential care to severely handicapped and elderly developmentally disabled persons. Nursing and convalescent homes are specifically designed to meet the needs of those who cannot take care of themselves, and who frequently require medical or nursing attention. Many such facilities also provide extensive opportunities for recreation and socialization (Ingalls 1978).

Independent living is considered the ideal living arrangement, the primary goal of most programs serving individuals with developmental disabilities. Obtaining their own apartment and living just like any other citizen in the community is the ultimate in normalization. Independent living training programs are the least restrictive alternatives within community residential settings. Individuals' needs determine the amount of supervision, support, and training required to obtain and maintain independent living.

There are several variations of the concept of independent living which will be discussed under the heading, "Program Effectiveness." In all the various settings,

money management, cooking, and household skills are the primary areas of instruction and support (Payne and Patton 1981).

Impetus for the Development of Independent Living Training Programs

There have been four major sociopolitical issues which have contributed toward the development of independent living training programs for individuals with developmental disabilities: the human rights movement, deinstitutionalization, normalization, and the concept of least restrictive environment. The human rights movement has positively affected the provision of specialized services for disabled persons. Through the movement, increased rights have been realized in the areas of treatment, education, and community participation. However, at times, professionals have questioned the methods used when implementing those human rights. For example, in certain residential settings, especially large institutions, disabled persons' rights have been denied by inhumane care (Haywood and Newbrough 1981).

Deinstitutionalization refers to the transition of disabled persons from institutional to community living. Historically, it was believed that developmentally disabled persons could best be served in large segregated environments. Hence, in the mid-1800s, increasing numbers of disabled individuals were moved from their homes into

institutions. The goal was to provide education and training in hopes of curing mental retardation and returning the disabled to community life. In the later 1800s, society aimed to protect "deviants" from the general population and vice versa--it was believed that mental retardation caused society's evils. With that emerging philosophy, the care and treatment became much more dehumanizing and placements were considered permanent. Another shift took place in the 1920s--it was believed that institutions could provide good custodial care for severely disabled individuals. They were no longer blamed for causing society's evils (Gollay and others 1978).

Beginning in the 1950s, parents of developmentally disabled children banded together to demand greater support and services. Along with citizen advocacy groups and professional organizations, they called attention to poor institutional care. However, there were few alternatives to institutions. Governmental agencies were soon pressured to develop appropriate residential alternatives. Legal action resulted in the division of large centralized facilities into smaller localized ones. Funding was established for group homes and other types of community residences. Policies mandating all state institutions to deinstitutionalize were implemented in the 1970s. Four expectations of deinstitutionalization were:

1. (Re)placement of all persons capable of living in a less restrictive setting;

2. Development of alternative living environments;

3. Upgrading of institutions; and

4. Restrictions on new admissions and tightening of entrance criteria (Gollay and others 1978; Wetzel and Hoschouer 1984; Willer and Intagliata 1984).

Normalization refers to "the utilization of means which are as culturally normative as possible, in order to elicit and/or maintain behaviors which are as culturally normative as possible" (Fritz and others 1971, p. 22). Normalization was initially established as the right of developmentally disabled persons to enjoy the same human services available to the non-disabled population. It became the philosophical basis for deinstitutionalization. Some practitioners believe that disabled persons need not be treated the same as non-disabled persons, but arrangements should be made to approximate the life-style of the disabled with that of the non-disabled. In so doing, the behavior and development of developmentally disabled persons would be less deviant. Normalization has become the foundation for many programs and has encouraged a reduction in the range of differences between settings for disabled and non-disabled persons (Haywood and Newbrough 1981; Willer and Intagliata 1984).

The concept of least restrictive environment refers to serving a disabled person in the least confining and most normalized setting consistent with his/her needs. It is a direct consequence of a judicial action regarding proper care and treatment of disabled persons. The appropriate residential setting must be decided on an individual basis; it must be compatible with the individual's needs, deficits, and strengths. The goal of residential and treatment centers is maximum liberty according to the mandates of the "least restrictive environment" (Haywood and Newbrough 1981).

Program Effectiveness

Considerable research has been conducted on the effects of the movement from institutions to community placements. The results are inconsistent. Rosen and others (1977) state that empirical studies of the effects of institutions have not been unanimous in documenting detrimental effects. Furthermore, when there is a consensus that institutions have a negative effect overall, it is not clear which variables are associated with which effects. The researchers cite studies which indicate that many community residences may be no better than the larger institutions (Rosen and others 1977).

On the other hand, Crnic and Pym (1979) cite several studies which document the success of various community placements. In fact, these authors assume that the

positive effects of deinstitutionalization are well documented. However, they indicate that little attention has been paid to independent living. A review of recent studies in this area will now be presented.

Baker and others (1977) differentiate semi-independent models from more restrictive settings on the basis of amount of supervision. Although the pattern of semi-independent and apartment residences varies, all provide less than 24 hour per day supervision. They describe several different models:

1. Group homes in which staff live with the residents but only provide training for a specified amount of time;

2. Group homes in which staff do not live with the residents but come in at specified times to provide instruction;

3. Apartment clusters in which several apartments are in close physical proximity and supervision is provided by staff who live in one of the apartments;

4. Single co-residence apartments in which one to two staff live with two to three developmentally disabled persons as roommates and friends; and

5. The single maximum independence apartment in which developmentally disabled persons share an apartment and receive instruction by an advocate or caseworker.

The common theme behind these models is normalization; the clients are given more independence and the staff assume a

greater degree of risk taking. From the semi-independent residences studied by Baker and others (1977), the high-potential, high-risk nature is evident--24% moved on to independent living and 23% returned to institutions.

In their own study, Crnic and Pym (1979) noted that over 100 individuals with developmental disabilities have moved from group homes to independent living in the State of Washington. Furthermore, it was estimated that approximately 1/3 of the group home residents could transition to independent living if appropriate community resources, suitable housing, and adequate supervision were available. Based on this assumption, an independent living project was designed in which 17 group home residents were given independent living skills instruction and placed in independent settings. Fourteen residents successfully made this transition. Adequate psychological and behavioral skills, along with accessibility of social support systems, were found to be the factors associated with successful independent living. For those clients who were not successful in the transition, the occurrence of overwhelmingly natural consequences of behavior (i.e., being evicted from an apartment because of not paying the rent), social isolation, and anxiety-induced behavioral regressions were the associated factors. The researchers concluded that, "Independence appears to be a qualified concept, in that it

is unlikely that these individuals will be able to function without some supervision" (Crnic and Pym 1979, p. 16).

Pagano, in Urban Community Care for the Developmentally Disabled, edited by Cohen and Kligler (1980), described a model of independent living for adults with developmental disabilities in New York. The program began in 1975 and by 1978 50 adults were living in their own apartments in 15 different Bronx neighborhoods. Pagano feels that the "success" of independent living can be interpreted in different ways; often the client, family, staff, case manager, and advocate disagree on what is optimal for the client. Quality of life also represents an area of conflict because independence does not necessarily mean higher quality according to societal standards. Pagano asserts that any independent living training program must be firmly grounded in the belief of dignity of risk. Staff must allow clients to make their own judgments and carry out their own decisions.

Schalock and others (1981) studied 69 developmentally disabled adults in Nebraska who had been placed from group homes into the less restrictive environments of apartments. Their work represented a five year longitudinal study. The authors defined successful placement as remaining in a staffed apartment or independent housing for five years; unsuccessful placement was defined as returning to a more restrictive setting including group, foster, or natural

homes. The results indicated that 80%, 55 residents, still resided in either their original apartment setting or had moved to a more independent setting. Of the 55 successful clients, 27 had been officially terminated from receiving any training services. This group was thought to be successful both in their independent placement and in competitive employment. Placement success was significantly related to behavioral skills in personal maintenance, clothing care and use, and community utilization. Skills in food preparation, time management, and communication became more important as the duration of the placement increased. Tested intelligence and functional academics were not related to placement success. Of the 14 clients whose placements were unsuccessful, inappropriate social behavior, inadequate nutrition, and insufficient skills in home maintenance were the primary factors.

Cox and others (1983) presented their descriptive study of developmentally disabled adults living in group homes, tenant support, and alternative living. Those clients in tenant support and alternative living are capable of maintaining their own homes with less than 24 hour per day supervision. They live as independently as possible. The tenant support clients receive a maximum of 120 hours per month of independent living skills training while the alternative living clients receive a maximum of 30 hours per month. The sample consisted of a total of 207

residents who were randomly selected from 8 counties in Washington. The total sample was broken down to include 82 residents of group homes, 68 of tenant support, and 57 of alternative living. Information was gathered from personal interviews with the clients and telephone interviews with residential staff, day training staff, case managers, parents, guardians, and advocates. Results indicated that the case managers believed the current living arrangements were satisfactory/very satisfactory for 89% of those clients living in group homes, 93% in tenant support, and 88% in alternate living. According to the views of the parents, 96% of the clients had satisfactory living arrangements in group homes, 95% in tenant support, and 82% in alternative living. Clients themselves liked their current residence as follows: 83% in group homes, 91% in tenant support, and 80% in alternative living. Overall, the greatest satisfaction appeared to be with the tenant support arrangement.

The most recent and comprehensive study of independent living training programs was published in 1986 by Halpern and others. The researchers studied the impact of "semi-independent living programs" for adults with mental retardation. Their definition of semi-independent living programs is the provision of limited and occasional assistance to clients typically living in apartment settings. Their descriptive study encompassed both qualitative and

quantitative data in the areas of client characteristics, quality of residential environments (apartments and neighborhoods), employment and financial security, quality of clients' interpersonal relationships and leisure activities, and program characteristics (administrative, service delivery patterns, and levels of community support). The study incorporated data gathered from clients, direct program staff, and administrative staff through the utilization of three separate questionnaires. The sample consisted of approximately 300 adults living in over 30 semi-independent living programs in California, Colorado, Oregon, and Washington. A six to eight month follow-up study was conducted to evaluate the stability of the original information gathered.

Halpern and others (1986) did not address the issue of "success" in terms of duration of independent or semi-independent living status. However, the thorough study certainly did provide very valuable information. Overall, the findings indicated were as follows:

1. Client characteristics--the population studied was mostly Caucasians between 20-30 years old, functioning in the mild range of mental retardation. Few experienced criminal offenses, behavior problems, or substance abuse. They possessed moderate skills in the area of independent living. Many had chronic health problems and secondary disabilities, and minor health problems were of normal

frequency. Motivation to participate in semi-independent living programs was quite variable although the majority expressed high levels of motivation. The majority of the clients also had positive self-concepts.

2. Quality of residential environments--the majority of the sample lived in relatively clean, integrated apartment complexes. The apartments were generally close to community resources and located in adequately clean residential neighborhoods. Most of the clients lived with one or two roommates, although 44% indicated a preference to live alone. The average cost of housing was $150 per month; many clients received subsidies. Safety, noise, crime, and undesirable neighborhoods or roommates were of concern to many clients.

3. Employment and financial security--of the sample, only 30% were unemployed, usually because of social deficits, interpersonal problems, or lack of motivation. Of the employed group, 37% worked in sheltered settings, while 29% were competitively employed. Average income was $428 per month; 37% were at or below the poverty level.

4. Quality of clients' interpersonal relationships and leisure activities--contact with family was very high; 95% of the clients engaged in either personal or telephone visits on a regular basis. Families provided an appropriate amount of help when needed to 75% of the clients. Most participants had a best friend, although more than half

claimed to be lonely frequently. The majority of single clients were involved in an ongoing relationship with a person of the opposite sex. Only 12% of the sample were married and 5% had children. Sex education had been provided to most clients, although many still had questions in this area. Favorite leisure activities paralleled those of the general population, for example, watching television and listening to music. The majority of the clients (86%) expressed satisfaction with their leisure activities. Social integration was not widely evident--only 1/3 of the clients' waking hours was spent with non-disabled people.

5. Program characteristics--semi-independent living programs are relatively new. The average length of operation was 3 years and the oldest was 10 years. An average of 20 clients participated in each program. Many services were provided to the clients through the living program itself and other community agencies. Services designed to manage behavior problems or to secure competitive employment were least available. Most services were well matched to the individual client's needs and abilities. Approximately 75% of staff time was spent on direct training with clients. The staff of the programs were generally well trained and educated; approximately 2/3 had college degrees and only 20% had no relevant work experience. Low salaries were probably the major contributing factor to high staff turnover rates. The majority of clients were

satisfied with their programs. However, 1/3 expressed a desire to move, usually for growth enhancing reasons. Approximately 1/3 felt that program rules were too restrictive.

In summary, the above studies have indicated several major considerations for effectiveness of independent living training programs. Psychological and behavioral skills are two determining factors of achieving successful independent living. Accessibility of community resources, including suitable housing, is also an important factor. In addition, clients who have strong social support systems, and some degree of continued supervision, are more likely to achieve and maintain independent living than those clients who lack support. Finally, program staff agree that allowing the clients to take risks and make their own decisions are necessary ingredients for an effective independent living training program (Cohen and Kligler 1980; Crnic and Pym 1979; Halpern and others 1986).

Chapter 3

Research Methodology

Research Design

After careful review of related literature, it was decided that a descriptive study utilizing case record reviews and follow-up telephone contacts would be the most appropriate method to address the problem statements. The two questions addressed by the study were formulated as follows:

1. Are independent living training programs in Los Angeles County effectively training individuals with developmental disabilities to live independently? and

2. Which client characteristics are associated with successful independent living?

For the purposes of the study, an independent living training program was defined as a residential apartment training program in which clients receive intensive skills training. Successful independent living was defined as living in the community alone or with a roommate for a minimum of six months after receiving the intensive skills training.

Instrument

Next, the researcher developed the first draft of the survey instrument. The items consisted of the following

client characteristics: current age, age when entered program, sex, level of mental retardation, presence of other developmental disabilities, presence of a dual diagnosis, and ethnicity. Program information was also included; this consisted of program of attendance, length of attendance, and status at termination of the program. In addition, information was collected about the clients' living situation immediately before attending the independent living training program, immediately after the program, six months after the program, and currently. Financial information and an open-ended question for comments were also part of the instrument.

The researcher pretested the instrument by conducting case record reviews and telephone surveys with two of her clients who had attended independent living training programs. Minor changes were indicated from the pretesting. The final draft of the instrument was then completed (Appendix A).

Sample

The researcher is employed in Los Angeles County in the field of developmental disabilities. She was aware of four independent living training programs in Los Angeles County which provided residential, intensive skills training. In order to determine if additional programs existed, the researcher contacted several regional centers in Los Angeles County, but located no additional programs. An

introductory letter was written and mailed to the administrators of the four programs (Appendix B). The purpose of the letter was to request the agencies' assistance and cooperation with the project. Two weeks after the letters were mailed, the researcher contacted each of the administrators by telephone to further explain the project and solicit their cooperation. Each administrator was asked to submit a letter stating their agency's willingness to cooperate in the project. Two of the four agencies sent letters; the other two gave verbal confirmations only.

The researcher then asked each of the program administrators to formulate a list of their clients who met the following criteria: developmentally disabled adults (18 years and older) who had participated in residential, intensive skills training for any length of time, and who exited the program for any reason (e.g., graduation, eviction, by choice) between June, 1984 and June, 1986. The two-year time span of exiting the programs was chosen because it allowed the researcher to examine the living situation of clients at least six months after they exited the training programs.

The researcher initially planned to survey a total of 50 clients who met the above criteria. Two of the programs had relatively small samples, 20 clients in one program, and 16 in the other. Therefore, it was decided to solicit the participation of all their clients, rather than

conducting a random sample from these programs. The two remaining programs had many clients who met the criteria. Therefore, the researcher utilized a random numbers table to select 16 potential participants from each program. It was at this time that one of the program administrators decided to not continue participation in the project. Thus, a list of 52 potential participants from 3 programs was formulated.

Consent to release information forms (Appendix C) were developed and mailed to the 52 clients, along with a cover letter explaining the project (Appendix D). Self-addressed stamped envelopes were provided for the return of the consent forms. There were 25 consent forms signed and returned within two weeks. The researcher then attempted to contact by telephone the 27 clients who had not yet returned the forms. Within two more weeks, eight additional forms were signed and returned. Therefore, a total of 33 clients agreed to participate in the study.

Data Collection

The researcher scheduled appointments with the three program administrators at their offices to review the case records. The researcher had intended to complete only a part of each survey at the program site/office. However, through case record reviews and discussions with the administrators, the researcher was able to complete the entire survey for each client. Follow-up telephone calls

were made to a few of the clients to verify information obtained from the case records and discussions with the administrators.

Data Analysis

Data analysis was completed on a computer using a dBase III Plus software program. Frequencies and percentages were computed for each survey item. Cross-tabulations of client/program characteristics and living situations were then performed. Chi-square tests were performed on some of the cross-tabulations to determine statistical significance. Finally, a written report was prepared which consisted of the results, discussion, summary, and recommendations.

Chapter 4

Results

Description of the Sample

The first step in analyzing the results of the 33 completed surveys was to tabulate each response item. Appendix E displays the results of the overall tabulation. Percentages were also computed for each response item. Table 1 shows that 76% of the clients were between the ages of 18 and 30 years when they entered the program. The population was split between males and females--19 males (58%) and 14 females (42%). A total of 31 participants (94%) functioned in the mild range of retardation; one participant (3%) was not mentally retarded and one (3%) was moderately retarded.

Table 1. Age When Entered Program

Age	Frequency	Percent
18-22	10	30
23-30	15	46
31-40	8	24
41-50	0	0
50+	0	0
Total	N = 33	100

As shown in Table 2, most of the participants (79%) did not have a developmental disability in addition to mental retardation; however, 4 (12%) had cerebral palsy and 3 (9%) had epilepsy. Seven participants (21%) had a dual diagnosis (mental illness in addition to mental retardation), as shown in Table 3. The ethnicity item (Table 4) indicated the majority of the clients were Caucasian--22 Caucasians (67%), 6 Blacks (18%), and 5 Hispanics (15%). In summary, a typical client could be described as a Caucasian male, under 30 years of age, functioning in the mild range of retardation, without other developmental disabilities or a dual diagnosis.

Table 2. Other Developmental Disabilities

Disability	Frequency	Percent
Autism	0	0
Cerebral Palsy	4	12
Epilepsy	3	9
Other	0	0
No additional developmental disability	26	79
Total	N = 33	100

Table 3. Dual Diagnosis

Dual Diagnosis	Frequency	Percent
Yes	7	21
No	26	79
Total	N = 33	100

Table 4. Ethnicity

Ethnicity	Frequency	Percent
Black	6	18
Caucasian	22	67
Hispanic	5	15
Total	N = 33	100

Program Information

The program items provided the following information. Of the participants, 13 (39%) attended one program (7 from one of their sites and 6 from the other site), 13 (39%) attended another program, and 7 (21%) attended the third program. Table 5 shows that 18 clients (55%) attended for 22 to 24 months and 4 clients (12%) attended over 2 years. Only one client (3%) attended his/her program for less than a year. The remaining 10 clients (30%) attended between 13 and 21 months. As shown in Table 6, the majority of the

clients (79%) graduated from their programs, but 3 (9%) were evicted, 2 (6%) left by choice, and 2 (6%) were referred to other services.

Table 5. Length of Attendance

Length (Months)	Frequency	Percent
0- 3	0	0
4- 6	0	0
7- 9	1	3
10-12	0	0
13-15	5	15
16-18	3	9
19-21	2	6
22-24	18	55
25+	4	12
Total	N = 33	100

Table 6. Status at Termination

Status	Frequency	Percent
Graduated	26	79
Evicted	3	9
Left by choice	2	6
Other-referred	2	6
Total	N = 33	100

Living Situations

Table 7 describes the clients' living situations for the four categories--prior to the independent living training program, immediately after the program (subsequent), six months after, and current. Note that "independent-alone" and "independent-roommate" are considered successful independent living; the other conditions are considered non-independent. Of the participants, 17 (52%) were living with their families prior to attending the independent living training program. Of the clients, 4 (12%) were living semi-independently and 12 (36%) were living in group homes. Immediately after the program, 23 clients (70%) lived independently--4 alone (12%) and 19 with roommates (58%). Of the clients, 2 (6%) moved into semi-independent situations, 3 (9%) moved in with their families, 4 (12%) into group homes, and one (3%) had no shelter.

Table 7 also indicates that 22 clients (67%) lived independently six months after leaving the independent living training program; 4 of these lived alone (12%) and 18 lived with roommates (55%). In addition, 3 (9%) were living semi-independently, 4 (12%) with their families, and 4 (12%) in group homes. The current living situation was described as follows: 23 clients (70%) were living independently, 3 (9%) were in semi-independent situations, 5 (15%) with their families, and 2 (6%) in group homes.

Table 7. Living Situation

Type	Prior #	Prior %	Subsequent #	Subsequent %	Six Months #	Six Months %	Current #	Current %
Independent								
Alone	0	0	4	12	4	12	4	12
Roommate	0	0	19	58	18	55	19	58
Non-Independent								
Semi-independent	4	12	2	6	3	9	3	9
Family	17	52	3	9	4	12	5	15
Group homes	12	36	4	12	4	12	2	6
No shelter	0	0	1	3	0	0	0	0
Total N =	33	100	33	100	33	100	33	100

For those clients not currently living independently, the following reasons were provided: 2 (6%) could not find housing, 3 (9%) required a supervised setting due to lack of skills, 3 (9%) required a supervised setting due to behavior problems, one (3%) required a supervised setting due to health reasons, and one (3%) was looking for a roommate.

Financial Information

Of the clients, 31 received Supplemental Security Income (SSI) as a monthly source of income. There were six clients who received Social Security (SSA) benefits.

Many of the clients had additional sources of income, the most common being sheltered employment. Other sources of income included in-home supportive services (IHSS), family, competitive employment, and supported work.

Comparisons

The next step in analyzing the results of the study was to perform cross-tabulations of client/program characteristics and living situations. For the purposes of the present study, successful independent living was defined as living in the community alone or with a roommate for a minimum of six months. Therefore, the most important cross-tabulations were those which combined client/program characteristics and the "six months after" living situation. Selected cross-tabulations are presented in Tables 8, 9, 10, 11, and 12. The significance of the information presented in each of these tables is discussed in Chapter 5.

Table 8. Cross-Tabulation of Status at Termination--Living Situation Six Months After

Status	Independent		Non-Independent		Total	
	#	%	#	%	#	%
Graduated	21	81	5	19	26	100
Not graduated	1	14	6	86	7	100

N = 33.

*Significant at the .005 level.

Table 9. Cross-Tabulation of Other Developmental Disabilities--Living Situation Six Months After

Disability	Independent #	Independent %	Non-Independent #	Non-Independent %	Total #	Total %
Cerebral Palsy	4	100	0	0	4	100
Epilepsy	3	100	0	0	3	100
No Add'l developmental disability	15	58	11	42	26	100

N = 33.

Table 10. Cross-Tabulation of Dual Diagnosis--Living Situation Six Months After

Dual Diagnosis	Independent #	Independent %	Non-Independent #	Non-Independent %	Total #	Total %
Yes	5	71	2	29	7	100
No	17	65	9	35	26	100

N = 33.

Table 11. Cross-Tabulation of Ethnicity--Living Situation Six Months After

Ethnicity	Independent #	Independent %	Non-Independent #	Non-Independent %	Total #	Total %
Black	2	33	4	67	6	100
Caucasian	16	73	6	27	22	100
Hispanic	4	80	1	20	5	100

N = 33.

Table 12. Cross-Tabulation of Length of Attendance--Living Situation Six Months After

Length (Months)	Independent #	Independent %	Non-Independent #	Non-Independent %	Total #	Total %
7- 9	0	0	1	100	1	100
13-15	1	20	4	80	5	100
16-18	2	67	1	33	3	100
19-21	1	50	1	50	2	100
22-24	15	83	3	17	18	100
25+	3	75	1	25	4	100

After the cross-tabulations were completed, statistical significance was tested by performing the chi-square test on many of the cross-tabulations. The only relationship which was statistically significant was status at termination of program (Table 8). When the response items were compressed into only two categories (graduated and not graduated), the correlation was significant at the .005 level.

Chapter 5

Discussion

Conclusions

The first problem statement was presented as: Are independent living training programs in Los Angeles County effectively training individuals with developmental disabilities to live independently? Successful independent living was defined as living in the community alone or with a roommate for a minimum of six months. The project results indicate that the independent living training programs in Los Angeles County are reasonably effective in training individuals with developmental disabilities to live independently. Item 13 on the overall tally (Appendix E) and Table 7 indicate that 22 participants (67%) achieved and maintained an independent living status for six months after receiving the training. Of these individuals, 18 (55%) were living with roommates and 4 (12%) were living alone. In addition, Table 8 indicates that 81% of those clients who completed (graduated) the programs were living independently after six months. It must be noted that the sample size was relatively small; a total of 33 clients were included in the survey.

The second problem statement was presented as: Which client characteristics are associated with successful

independent living? According to the chi-square tests, none of the client characteristics were significantly correlated with successful independent living. However, the program characteristic, status at termination of program, was statistically significant (Table 8). This is not surprising; it is a rather obvious correlation--it should be expected that those clients who graduate are more likely to live independently than those who do not graduate. Furthermore, those clients who lack potential to live independently are more likely to exit the programs early, either by eviction, choice, or referral elsewhere.

Although none of the client characteristics were associated with successful independent living at a statistically significant level, several relationships were strong enough to have practical significance. Primarily, it must be remembered that the sample consisted mainly of young (18 to 30 years) mildly retarded Caucasian individuals who did not have another developmental disability or a dual diagnosis. It can be assumed that these characteristics describe the typical client referred to, and accepted by, independent living training programs in Los Angeles County.

Furthermore, the client characteristic of "other developmental disabilities" provides interesting information. Four clients had cerebral palsy and three had epilepsy. All seven of these clients achieved and

maintained an independent living status for a minimum of six months (Table 9). If the sample is assumed to be representative, it may be that the existence of an additional developmental disability does not interfere with successful independent living.

Seven participants in the study had a dual diagnosis--the same number that had an additional developmental disability. Although the results are not as conclusive, it is also suggested that having a dual diagnosis does not interfere with maintaining successful independent living. As shown in Table 10, 71% (5 out of 7) of those clients with a dual diagnosis achieved and maintained an independent living status for a minimum of six months. This figure is above the percentage of the total sample who were living independently after six months (67%) as shown in Table 7.

Item 7, ethnicity, is worthy of discussion. According to Table 11, 33% of the Blacks were living independently after six months. A much higher percentage of Caucasians and Hispanics, 73% and 80% respectively, were living independently after six months. Although the total sample size was small, the ethnicity information may have important implications for program planning. Individual socioeconomic factors, such as financial status, and societal issues, such as racism and discrimination, may differentially affect the ability of clients to succeed in

independent living training programs. Such differences may need to be taken into account when developing clients' individual program plans.

The length of attendance item also provides noteworthy information. As shown in Table 12, 83% of those clients who attended an independent living training program for 22 to 24 months were living independently after six months. Of those who attended a program for more than two years, 75% were living independently after six months. However, only 20% of those clients who attended 15 months or less were living independently after six months. Therefore, it appears that longer attendance increases the probability of achieving and maintaining an independent living status.

In summary, the following conclusions are presented. Independent living training programs in Los Angeles County have been reasonably effective in training individuals with developmental disabilities to live independently. Of the 33 participants in the study, 67% were living independently six months after exiting the programs. Status at termination of the program was the only variable which showed a statistically significant correlation with successful independent living; those clients who graduate from the programs are more likely to achieve and maintain independent living. Other variables which deserved practical significance were the client characteristics of "other developmental disabilities," "dual diagnosis," ethnicity,

and the program item "length of attendance." Having an additional developmental disability or a dual diagnosis did not seem to interfere with the probability of achieving and maintaining an independent living status. However, ethnicity did appear to relate to the probability of achieving successful independent living--Blacks were less successful than Caucasians and Hispanics. And, finally, those clients who attended independent living training programs for a minimum of 22 months were more likely to succeed in independent living than those who attended for a shorter time.

Recommendations

As a result of this study, the author makes the following recommendations:

1. A similar study should be conducted which follows more clients over a longer period of time. Optimally, the researchers would incorporate extensive qualitative data, such as that described in the Halpern and others (1986) study, with quantitative data related to the effectiveness of independent living training programs.

2. As none of the correlations between client characteristics and successful independent living were statistically significant, further research should investigate the effects of other variables. For example, the effects of post-training activities and/or behaviors should be investigated. A possible question is, "Do

follow-up services (limited training to help clients maintain an independent living status) increase the probability that clients will maintain independent living for a longer time?"

3. The staff of funding agencies and the service providers should examine the relative effectiveness of the different types of independent living training programs. The three programs investigated in the present study have very different structures. It was not the intent of this author to compare the different programs; however, such a comparison could provide valuable information.

Appendices

Appendix A

Survey

IDENTIFYING DATA

Code Number:

Name:

Address:

Phone Number:

Parent/Guardian:

Phone Number:

I.L.S. Program:

Dates of Attendance:

FOLLOW-UP SURVEY
OF
DEVELOPMENTALLY DISABLED CLIENTS
WHO PARTICIPATED IN
RESIDENTIAL INDEPENDENT LIVING TRAINING PROGRAMS
IN LOS ANGELES COUNTY

Participant Number:
Date(s):

I. Record Review

1. Current age
___18-22 (0) ___23-30 (1) ___31-40 (2) ___41-50 (3)
___50+ (4)

2. Age when entered program
___18-22 (0) ___23-30 (1) ___31-40 (2) ___41-50 (3)
___50+ (4)

3. Sex
___Male (0) ___Female (1)

4. Level of mental retardation
___Not MR (0) ___Mild (1) ___Moderate (2) ___Severe (3)
___Profound (4) ___Unknown (5)

5. Other developmental disabilities
___Autism (0) ___Cerebral Palsy (1) ___Epilepsy (2)
___Other neurological (3) ___None (4)

6. Dual diagnosis (Code NO if not recorded in chart)
___Yes (0) ___No (1)

7. Ethnicity
___Asian (0) ___Black (1) ___Caucasian (2)
___Hispanic (3) ___Native American (4)
___Other (5) Specify_____

8. Independent living program
___A (0) ___B (1) ___C (2) ___D (3) ___E (4) ___F (5)
___G (6)

9. Length of attendance
___0-3 months (0) ___4-6 months (1) ___7-9 months (2)
___10-12 months (3) ___13-15 months (4)
___16-18 months (5) ___19-21 months (6)
___22-24 months (7) ___25+ months (8)

10. Status at termination of program
___Graduated (0) ___Evicted (1) ___Left by choice (2)
___Other (3) Specify_____

II. Telephone Contact (The following information will be gathered by asking open-ended questions as shown; the interviewer will code the response into the appropriate category.)

A. Living situation

	11.	12.	13.	14.
(0) Independent--alone	___	___	___	___
(1) Independent--w/roommate	___	___	___	___
(2) Semi-Independent (some sup.)	___	___	___	___
(3) With own family	___	___	___	___
(4) Small group home (1-6 beds)	___	___	___	___
(5) Large group home (7+ beds)	___	___	___	___
(6) Intermediate care facility	___	___	___	___
(7) Skilled nursing facility	___	___	___	___
(8) State hospital/Dev. center	___	___	___	___
(9) Hotel/Motel	___	___	___	___
(10) No shelter	___	___	___	___
(11) Other, Specify_____	___	___	___	___
(12) Unknown	___	___	___	___

11. PRIOR LIVING SITUATION (Where did you live immediately before the independent living training program?)
12. SUBSEQUENT LIVING SITUATION (Where did you live immediately after the independent living training program?)
13. SIX MONTHS AFTER (Where did you live six months after you left the independent living training program?)
14. CURRENT LIVING SITUATION (Where do you live now?)

15. If currently not living independently, why?
___Lack of finances (0)
___Could not find housing (1)
___Chose to live with family (2)
___Chose to live with other relatives or friends (3)
___Required supervised setting due to lack of skills (4)
___Required supervised setting due to behavior problems (5)
___Required supervised setting due to health reasons (6)
___Other (7) Specify_____
___Unknown (8)
___Not applicable, living independently (9)

16. Please tell me your monthly source(s) of income. (Interviewer will give examples.)
___SSI (0)
___SSA (1)
___IHSS (2)
___Family (3)
___Competitive employment (4)
___Sheltered employment (5)
___Other (6) Specify _____
___None (7)
___Unknown (8)

17. Additional comments (Is there anything you want to add?) (Use other side if more room is necessary)

Appendix B

Letter to Program Administrators

CALIFORNIA STATE UNIVERSITY, LONG BEACH

MASTERS OF SOCIAL WORK

October 20, 1986

I am writing to request your assistance and cooperation with my graduate research project. I am a Contract Client Program Co-ordinator for Eastern Los Angeles Regional Center and also a graduate student in the Master of Social Work (MSW) program at California State University, Long Beach. The topic of my study is the effectiveness of independent living training programs in Los Angeles County for individuals with developmental disabilities. I have selected this topic because of personal interest and experience with such programs. I trust that the study will be valuable to program administrators by providing new data regarding the characteristics and outcomes of developmentally disabled persons who received independent living training. Ultimately, the study will benefit current and future participants of these programs.

I plan to conduct a follow-up survey of 50 randomly selected clients who exited (graduated or terminated) the various residential independent living training programs in Los Angeles County between June, 1984, and June, 1986. Your assistance is necessary to 1.)identify those clients who meet the above criteria; 2.)provide me with their names, addresses, and phone numbers; and 3.) provide access to their case records at your program site/office. After I obtain the clients' written consents, I will gather most of the survey information from their case records. I will then make follow-up telephone calls to the clients to determine their current living status. Please note that all information will be anonymous; clients and programs will not be individually identified. The project will be cleared by the University Protection of Human Subjects Committee.

Department of Social Work, Long Beach, California 90840

I appreciate your consideration of involvement in this project. I sincerely believe that the results will assist you with program planning and design. A summary of the project results will be available to you, your staff, and clients. I will contact you by phone in early November to discuss the details of the study and address any of your questions or concerns.

Sincerely,

Nancy E. White

Appendix C

Client Consent Form

CONSENT FOR RELEASE OF INFORMATION

Name:_____ Code Number:_____

I, _____ (Name), hereby consent to and authorize Nancy White to review my case record at _____ (Independent Living Training Program) and to complete a survey from the information in my case record.

I also consent to and authorize Nancy White to call me to gather additional information for the survey. I understand that she will talk to me for approximately ten minutes. I also understand that it is OK for me not to answer any questions.

_____ Date

_____ Participant Signature

_____ Phone Number

_____ Conservator Signature (if applicable)

Appendix D

Cover Letter to Clients

Nancy White
P.O. Box 491
Whittier, CA 90608

January 8, 1987

Dear

Hello. My name is Nancy White. I am a Social Work student at California State University, Long Beach. I am doing a research study about developmentally disabled persons who participated in independent living training programs. The study could help agencies to run better programs for developmentally disabled persons.

I NEED YOUR HELP! I understand that you attended _____ _____. I would like to do two things to learn more about you and the program you attended. First, I would like to look at you file at _____. Second, I would like to call you to ask questions about where you live and who you live with. I will talk to you for about ten minutes. This will give you a chance to express your feelings about the training you received. If you did not like your training program, it could upset you to talk to me, but I really don't think this will happen. I will be filling out a survey when I read your file and talk to you.

Before I look at your file or talk to you, I must have your permission. It is your choice if you want to participate in my study or not. If you want to participate, please sign the enclosed consent form and send it to me in the envelope that I already addressed and stamped. Also, if you change your mind and decide not to participate, that is OK. If you do not want to participate, nothing bad will happen to you.

I want you to know that I will not be copying any of your records. Also, any information I learn about you will be confidential. Your name will not be on the survey and I will not mention your name in my study.

Thank you very much for your help. If you have any questions, please call me at (213)699-1681. If I am not home, please leave a message on my answering machine and I will call you.

Sincerely,

Nancy White

Nancy White

Appendix E

Overall Tally

FOLLOW-UP SURVEY
OF
DEVELOPMENTALLY DISABLED CLIENTS
WHO PARTICIPATED IN
RESIDENTIAL INDEPENDENT LIVING TRAINING PROGRAMS
IN LOS ANGELES COUNTY

Participant Number:
Date(s):

I. Record Review

1. Current age
1 18-22 (0) 20 23-30 (1) 11 31-40 (2) 1 41-50 (3)
0 50+ (4)

2. Age when entered program
10 18-22 (0) 15 23-30 (1) 8 31-40 (2) 0 41-50 (3)
0 50+ (4)

3. Sex
19 Male (0) 14 Female (1)

4. Level of mental retardation
1 Not MR (0) 31 Mild (1) 1 Moderate (2) 0 Severe (3)
0 Profound (4) 0 Unknown (5)

5. Other developmental disabilities
0 Autism (0) 4 Cerebral Palsy (1) 3 Epilepsy (2)
0 Other neurological (3) 26 None (4)

6. Dual diagnosis (Code NO if not recorded in chart)
7 Yes (0) 26 No (1)

7. Ethnicity
0 Asian (0) 6 Black (1) 22 Caucasian (2)
5 Hispanic (3) 0 Native American (4)
0 Other (5) Specify_____

8. Independent living program
7 A (0) 6 B (1) 13 C (2) 0 D (3) 0 E (4) 0 F (5)
7 G (6) (A and B are two sites of one program)

9. Length of attendance
0 0-3 months (0) 0 4-6 months (1) 1 7-9 months (2)
0 10-12 months (3) 5 13-15 months (4)
3 16-18 months (5) 2 19-21 months (6)
18 22-24 months (7) 4 25+ months (8)

10. Status at termination of program
26 Graduated (0) 3 Evicted (1) 2 Left by choice (2)
2 Other (3) Specify referred to other services

II. Telephone Contact (The following information will be gathered by asking open-ended questions as shown; the interviewer will code the response into the appropriate category.)

A. Living situation

	11.	12.	13.	14.
(0) Independent--alone	___	4	4	4
(1) Independent--w/roommate	___	19	18	19
(2) Semi-Independent (some sup.)	4	2	3	3
(3) With own family	17	3	4	5
(4) Small group home (1-6 beds)	3	1	1	1
(5) Large group home (7+ beds)	9	3	3	1
(6) Intermediate care facility	___	___	___	___
(7) Skilled nursing facility	___	___	___	___
(8) State hospital/Dev. center	___	___	___	___
(9) Hotel/Motel	___	___	___	___
(10) No shelter	___	1	___	___
(11) Other, Specify_____	___	___	___	___
(12) Unknown	___	___	___	___

11. PRIOR LIVING SITUATION (Where did you live immediately before the independent living training program?)
12. SUBSEQUENT LIVING SITUATION (Where did you live immediately after the independent living training program?)
13. SIX MONTHS AFTER (Where did you live six months after you left the independent living training program?)
14. CURRENT LIVING SITUATION (Where do you live now?)

15. If currently not living independently, why?
___Lack of finances (0)
2 Could not find housing (1)
___Chose to live with family (2)
___Chose to live with other relatives or friends (3)
3 Required supervised setting due to lack of skills (4)
3 Required supervised setting due to behavior problems (5)
1 Required supervised setting due to health reasons (6)
1 Other (7) Specify looking for roommate
___Unknown (8)
23 Not applicable, living independently (9)

16. Please tell me your monthly source(s) of income. (Interviewer will give examples.)
31 SSI (0)
6 SSA (1)
1 IHSS (2)
2 Family (3)
3 Competitive employment (4)
16 Sheltered employment (5)
8 Other (6) Specify Supported work
___None (7)
___Unknown (8)

17. Additional comments (Is there anything you want to add?) (Use other side if more room is necessary) NO COMMENTS

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